

**Office of Rare Diseases Research Global Rare Diseases Patient Registry and Data Repository-GRDR
Minimal Common Data Elements (CDEs)**

Element Number	Element Name	Question Text	Element Definition	Permissible Values	Data Source and/or Data Type	Link to Data Source and/or Data Type	Elements selected as "Required" by the steering committee are marked v
Current Contact Information							
1	Date of registry record	Date report is filled out or registry information is updated	A date or date and time value.	Non-enumerated Display Format YYYY/MM/DD	International Organization for Standards (ISO) HL7 DT data type (http://www.hl7.org/)	http://www.iso.org/iso/support/faqs/faqs_widely_used_standards/widely_used_standards_other/date_and_time_format.htm http://www.hl7.org/	v
2	First name of patient	Patient first name as recorded in birth certificate or passport	A word or group of words indicating a person's first (personal or given) name; the name that precedes the surname. Synonym = Given Name.	Name as appears in official documents e.g. passport and birth certificate	HL7 ST data type	(http://www.hl7.org/)	v
3	Last name of patient	Patient last name	A means of identifying an individual by using a word or group of words indicating a person's last (family) name. Synonym = Last Name, Surname.	Name as appears in official documents e.g. passport and birth certificate	HL7 ST data type	(http://www.hl7.org/)	v
4	Middle name of patient	Patient middle name	A means of identifying an individual by using a word or group of words indicating a person's middle name.	Name as appears in official documents e.g. passport and birth certificate or NA	HL7 ST data type	(http://www.hl7.org/)	v
5	Patient address: street	Street name	A component of an address that specifies a location by formatted concatenation of street/thoroughfare address components as described by a derivation rule.	Text	HL7 ST data type	http://www.hl7.org/	v
6	Patient address: city, town or village	City name	A component of an address that specifies a location by identification of a city, town, or village.	Text	HL7 ST data type	(http://www.hl7.org/)	v

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7	Patient address: state or province	State or province name	A component of an address that specifies a location by identification of a principal administrative unit of a country.	Text	Official designation by country. For USA & Canada, see accompanying document for full list.	USA: http://www.usps.com/ncsc/lookups/usps_abbreviations.html Canada: http://www.canadapost.ca/tools/pg/manual/PGaddress-e.asp#1380608	v
8	Patient address: zip/postal code	Zip/Postal Code	The string of characters used to identify the five-digit Zone Improvement Plan (ZIP) code and the four-digit extension code (if available) that represents the geographic segment that is a subunit of the ZIP code, assigned by the U.S. Postal Service to a geographic location to facilitate mail delivery; or the postal zone specific to the country, other than the U.S., where the mail is delivered.	numerical or combination of letters and numbers			v
9	Patient country	Country of primary address	the two-letter code of values representing the countries of the world for the address of a person.	248 two letter country codes	ISO 3166-1alpha-2 code	ISO 3166-1alpha-2 code http://www.iso.org/iso/english_country_names_and_code_elements	v
10	Patient Email address	Email Address	The string of characters that represents the electronic mail address of a person	Text or NA			v

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11	Patient telephone number-primary	Telephone Number	The number that identifies a particular telephone connection [Explanatory comment: The preferred format for telephone number is +CCC(AAA)LLLLLLLL/XXXXX where +CCC is the country code, (AAA) is the area code, LLLLLLLL is the local code and XXXXX is the extension number. Partial numbers may be filled from the left, e.g., + (AAA)LLLLLLLL/XXXXX (country code unknown or not necessary), + ()LLLLLLLL/, (country code, area code, and extension unknown or not necessary), etc.]	Numerical number	HL7 TN data type	http://www.hl7.org/	v
12	First name of secondary contact	First name of Secondary Contact	A word or group of words indicating a person's first (personal or given) name; the name that precedes the surname.	Name as appears in official documents e.g. passport and birth certificate	HL7 ST data type	(http://www.hl7.org/)	v
13	Last name of secondary contact	Last name of secondary contact	A means of identifying an individual by using a word or group of words indicating a person's last (family) name. Synonym = Last Name, Surname.	Name as appears in official documents e.g. passport and birth certificate	HL7 ST data type	(http://www.hl7.org/)	v
14	Middle name of secondary contact	Middle name of secondary contact	A means of identifying an individual by using a word or group of words indicating a person's middle name.	Name as appears in official documents e.g. passport and birth certificate NA	HL7 ST data type	(http://www.hl7.org/)	Optional
15	Secondary contact relationship	The relationship of the secondary contact to the patient	Relationship to the patient of the person designated by the patient as secondary contact	parent caregiver other relative other person	HL7 Table 0063 (v2.5)	(http://www.hl7.org/) http://www.hl7.org/special/committees/vocab/V26_Appendix	v

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16	Secondary contact: street	Street, secondary contact	A component of an address that specifies a location by formatted concatenation of street/thoroughfare address components as described by a derivation rule.	Text	HL7 ST data type	(http://www.hl7.org/)	v
17	Secondary contact: city	City, secondary street contact	A component of an address that specifies a location by identification of a city, town, or village.	Text	HL7 ST data type	(http://www.hl7.org/)	v
18	Secondary contact: state or province	State or province, secondary contact	A component of an address that specifies a location by identification of a principal administrative unit of a country.	Text	Official designation by country. For USA & Canada, see accompanying document for full list.	USA: http://www.usps.com/ncsc/lookups/usps_abbreviations.html Canada: http://www.canadapost.ca/tools/pg/manual/PGaddress-e.asp#1380608	v
19	Secondary contact: Zip/Postal Code	Zip/Postal Code, secondary contact	The string of characters used to identify the five-digit Zone Improvement Plan (ZIP) code and the four-digit extension code (if available) that represents the geographic segment that is a subunit of the ZIP code, assigned by the U.S. Postal Service to a geographic location to facilitate mail delivery; or the postal zone specific to the country, other than the U.S., where the mail is delivered.	Numerical number or combination of numerical number & letters			v
20	Secondary contact: country	Country, secondary contact	the free-text field to identify the geographic name or location of a person, place, or thing related to the territory of a nation.	Text	See accompanying document for full list of English names	ISO 3166: http://www.iso.org/iso/english_country_names_and_code_elements	v

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21	Secondary contact: telephone number	Telephone Number of secondary contact	The number that identifies a particular telephone connection [Explanatory comment: The preferred format for telephone number is +CCC(AAA)LLLLLLLL/XXXXX where +CCC is the country code, (AAA) is the area code, LLLLLLLL is the local code and XXXXX is the extension number. Partial numbers may be filled from the left, e.g., + (AAA)LLLLLLLL/XXXXX (country code unknown or not necessary), + ()LLLLLLLL/, (country code, area code, and extension unknown or not necessary), etc.]	Numerical number	HL7 TN data type	http://www.hl7.org/	v
22	Data entered by anyone other than patient	Is data entered by anyone other than the patient?	An identifier that references if anyone other than the patient enters data about the patient or on the patient's behalf.	Yes No	See accompanying document for HL7 HL7 table 0163	(http://www.hl7.org/) HL7 table 0163	v
23	Name of registrar	Name of person entering data in the registry	A formatted means of uniquely identifying an individual derived from multiple naming elements.	Text	HL7 XPN data type	(http://www.hl7.org/)	v
24	Relationship of registrar to patient	The relationship to the patient of the person entering the data in the registry,	The state of connectedness between the person recording the data in the registry and the patient.	patient/self parent caregiver other relative other person	HL7 Table 0063	(http://www.hl7.org/)	v
25	Consent to enter patient's data	When patient >18 years, was consent given to enter patient's data?	Consent to enter data on behalf of the patient's when patient is > 18 years and unable to enter his own data.	Yes	HL7 table 0163	(http://www.hl7.org/)	v

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26	Assent to enter patient's data	When patient < 18 years or If patient not competent to provide consent, was assent given by patient to enter patient's data?	Assent to enter data on behalf of the patient's when the patient is not competent to provide consent and enter his own data.	Yes Unable to assent			v
Socio-demographic							
27	Date of birth	Date patient was born as recorded in birth certificate or passport	The month, day and year on which the person was born.	Display Format YYYY/MM/DD	International Organization for Standards (ISO) HL7 DT data type	http://www.iso.org/iso/support/faqs/faqs_widely_used_standards/widely_used_standards_other/date_and_time_format.htm http://www.hl7.org/	v
28	Date of death	Date patient died (if applicable)	The actual date of a patient's/participant's death.	Display Format YYYY/MM/DD	International Organization for Standards (ISO) HL7 DT data type	http://www.iso.org/iso/support/faqs/faqs_widely_used_standards/widely_used_standards_other/date_and_time_format.htm http://www.hl7.org/	v

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29	Biological sex (genotype)	Sex of the patient at the time of birth e.g. female, male or any designation in between.	The textual representation of the sex of a person based upon genotyping. Genotyping is the genetic constitution of the individual; the characterization of the genes. [Explanatory Comment 1: Identification is based upon genotyping.] [Explanatory Comment 2: Genotyping is the genetic constitution of the individual; the characterization of the genes	XX genotype/Female XY genotype/Male XXX XXY (Klinefelter's Syndrome) XXXY Syndrome XXYY Syndrome Mosaic including XXXXY Penta X Syndrome XYY XO (Turner's Syndrome)	An International System for Human Cytogenetic Nomenclature (ISCN 2009)	http://content.karger.com/ProdukteDB/produkte.asp?Aktion=showproducts&searchWhat=books&ProduktNr=244102	v
30	Societal Sex (phenotype)	Self-identified gender	Text designations that identify gender. Gender is described as the assemblage of properties that distinguish people on the basis of their societal roles. [Explanatory Comment 1: Identification of gender is based upon self-report and may come from a form, questionnaire, interview, etc.]	A=Ambiguous F=Female M=Male N=Not applicable O=Other U=Unknown MFT=Male-to-female transsexual FMT=Female-to-male transsexual	HL7 Table 0001 (with additions). Also included in the accompanying document.	http://www.hl7.org/	v
31	Race	Self-reported race of the patient	The text for reporting information about race based on the OMB categories.	American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or other Pacific Islander, Not Reported, White	Office of Management Budget (OMB)	http://www.census.gov/population/www/socdemo/race/Ombdir15.html	v

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32	Ethnicity	Self-reported ethnicity of the patient	The text for reporting information about ethnicity	Hispanic or Latino, Not Hispanic or Latino, Not Reported, Unknown	OMB	http://www.census.gov/population/www/socdemo/race/Ombdir15.html	v
33	Nationality	Nationality (country)	The name of a country from which a person or their biological family had previous residence or past ancestors.	There is no constrained list of values from which to choose.	ISO 3166	ISO 3166: http://www.iso.org/iso/english_country_names_and_code_elements	Optional
34	Country of Birth	Birth Country	The type or name of the country in which a person was born.	USA, USA, specify the 2 letter State code (e.g. NY) Other country, Other country specify	ISO 3166	ISO 3166: http://www.iso.org/iso/english_country_names_and_code_elements	v
35	State or province of birth	State or province of birth	If the country of birth = USA or Canada, the administrative subunit of a state or provincen which a person was born.	Text	For USA & Canada, see accompanying document for full list.	USA: http://www.usps.com/ncsc/lookups/usps_abbreviations.html Canada: http://www.canadapost.ca/tools/pg/manual/PGaddress-e.asp#1380608	Optional
36	City, town or village of birth ¹	City, town or village name (as it appears on the birth certificate)	A component of an address that specifies a location by identification of a city, town, or village..	Text	HL7 ST data type	(http://www.hl7.org/)	v

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37	Insurance Type	Type of health insurance	A particular kind of mechanism (insurance) a person has for guarding against health-related risks, typically through the payment of premiums.	Government Arizona Health Care Cost Containment System (AHCCCS), Medicaid Medicare Medical Expenditure Panel Survey (MEPS) for private plans: Indemnity Preferred Provider Organization (PPO) Exclusive Provider Organization (EPO) Health Maintenance Organization (HMO) Individual Practice Association (IPA) Point-of-service (POS) No insurance Unknown	Agency for Healthcare Research & quality (AHRQ-modified)	Private plans: http://www.mepsahrq.gov/mepsweb/survey_comp/ic_ques_glossary.shtml#I	Optional

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38	Educational attainment-Registrant (if child, <18 years of age)	The grade the patient/child (younger than 18 years) is in now, in school, if home-schooled, the grade equivalent. If it is summer, the grade they just <u>completed</u> .	A subdivision of the demographic parameter indicating the highest level of education attained by a human being.	No schooling completed Nursery school Kindergarten Grade 1 Grade 2 Grade 3 Grade 4 Grade 5 Grade 6 Grade 7 Grade 8 Grade 9 Grade 10 Grade 11 Grade 12 - No Diploma Regular high school diploma GED or alternative credential Some college credit, but less than 1 year of college credit 1 or more years of college credit, no degree Associate's degree Bachelor's degree Master's degree Professional degree beyond a bachelor's degree Doctorate degree Unknown	American Community Survey (ACS) questionnaire, US Census Bureau ("Person 1" question 11):	http://www.census.gov/acs/www/Downloads/questionnaires/2011/Quest11.pdf	Optional

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39	Educational attainment- Registrant (if child, >18 years of age)	Level of education of the patient who is older than 18 years	The subdivision that summarizes the highest level of education attained by a person.	No schooling completed Some primary or high school - No Diploma Regular high school diploma GED or alternative credential Some college credit, but less than 1 year of college credit 1 or more years of college credit, no degree Associates degree Bachelor's degree Master's degree Professional degree beyond a bachelor's degree Doctorate degree Unknown	American Community Survey (ACS) questionnaire, US Census Bureau ("Person 1" question 11):	http://www.census.gov/acs/www/Downloads/questionnaires/2011/Quest11.pdf (Modified to reduce granularity related to grade level.)	Optional

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40	Educational attainment-mother	Level of education of the patient's mother	The subdivision that summarizes the highest level of education attained by a person.	No schooling completed Some primary or high school - No Diploma Regular high school diploma GED or alternative credential Some college credit, but less than 1 year of college credit 1 or more years of college credit, no degree Associates degree Bachelor's degree Master's degree Professional degree beyond a bachelor's degree Doctorate degree Unknown	American Community Survey (ACS) questionnaire, US Census Bureau ("Person 1" question 11):	http://www.census.gov/acs/www/Downloads/questionnaires/2011/Quest11.pdf (Modified to reduce granularity related to grade level.)	Optional

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41	Educational attainment-father	Level of education of the patient's father	The subdivision that summarizes the highest level of education attained by a person.	No schooling completed Some primary or high school - No Diploma Regular high school diploma GED or alternative credential Some college credit, but less than 1 year of college credit 1 or more years of college credit, no degree Associates degree Bachelor's degree Master's degree Professional degree beyond a bachelor's degree Doctorate degree Unknown	American Community Survey (ACS) questionnaire, US Census Bureau ("Person 1" question 11):	http://www.census.gov/acs/www/Downloads/questionnaires/2011/Quest11.pdf (Modified to reduce granularity related to grade level.)	Optional

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42	Family income -	What is patient's annual gross household income?	The total annual gross income of a household including the patient.	Less than \$10000 (USD) \$10000 - \$14999 \$15000 - \$19999 \$20000 - \$24999 \$25000 - \$29999 \$30000 - \$34999 \$35000 - \$39999 \$40000 - \$44999 \$45000 - \$49999 \$50000 - \$54999 \$55000 - \$59999 \$60000 - \$74999 \$75000 - \$84999 \$85000 - \$99999 \$100000 - \$149999 \$150000 - \$199999 \$200000 - \$249999 \$250000 and above Unknown Declines to provide	US government census	http://www.census.gov/compendia/statab/cats/income_expenditures_poverty_wealth/family_income.html -> Tables 694, 695	Optional
43	How many persons live in the household?	Number of people living in the household, including patient	The total number of people living in the same house as the patient in the past year (including the patient)	Numerical number			Optional
44	How many persons live in the group house	Number of people living in the group house including patient	The total number of people living in the same group house as the patient in the past year (including the patient)	Numerical number			Optional
Diagnosis							
45	Name of rare disease or condition	Descriptive disease label for the rare disease	The text that describes the rare diseases, syndromes and conditions.	List of Values to be identified from controlled vocabulary source	Office of Rare Disease Research, National Institute of Health	http://rarediseases.info.nih.gov/GARD/	v

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46	Date of rare disease or condition diagnosis	Date when the rare disease diagnosis was made	The date of the procedure or evaluation used to determine the diagnosis	Display Format YYYYMMDD	HL7 DT data type	http://www.hl7.org/	v
47	Age of rare disease or condition diagnosis ²	The age of the patient when the rare disease diagnosis was made	The age of the patient when the procedure or evaluation used to determine the diagnosis	Display format - Numeric-number of only one unit: weeks, months or years	HL7 TQ1 segment (TQ1-6)	http://www.hl7.org/	v
48	Date when disease or condition symptoms first observed	Date when patient first began experiencing symptoms or signs of the rare disease	A symptom is a departure from normal function or feeling which is noticed by a patient, indicating the presence of disease or abnormality. A symptom is subjective, observed by the patient, and not measured.	Display format - YYYYMMDD	HL7 DT data type	http://www.hl7.org/	v
49	Age when disease or condition symptoms first observed ²	Age when patient first began experiencing symptoms or signs of the rare disease	A symptom is a departure from normal function or feeling which is noticed by a patient, indicating the presence of disease or abnormality. A symptom is subjective, observed by the patient, and not measured.	Display format - Numeric-number of only one unit: weeks, months or years	HL7 TQ1 segment (TQ1-6)	http://www.hl7.org/	v

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50	How diagnosis was made	A non-mutually exclusive list of diagnostic tests and observations	The basis by which the diagnosis is made.	Genetic laboratory analysis Histology History Imaging - CT Imaging - MRI Imaging - PET Physical examination Other modality Unknown		(There is no standard answer list for this question.)	v
Family History							
51	Family history with the same rare disease or condition	Any known family member with the same disease	A family relative that is one or two meioses away from a particular individual in the family; a relative with whom one half (first degree) of an individual's genes is shared or a relative with whom one quarter (second degree) of an individual's genes is shared.	Daughter Son Mother Father Sister Brother Aunt uncle Niece Nephew First cousin First Cousin Once Removed Cousin No Unknown	HL7 table 0063 (modified from v2.5.1) See accompanying document for full list.	http://www.hl7.org/	v

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Birth & Reproductive History							
52	Birth Weight	Patient's birth weight in grams/kilograms or pounds/ounces	Value of a person's measured weight at birth plus second caDSR item for units: The Unified Code for Units of Measure symbols that represent a determinate amount or quantity used as the standard of measurement for the vertical force exerted by the mass of an individual as a result of gravity.	g kg [lb_av] [oz_av]	The Unified Code for Units of Measure (UCUM)	UCUM: http://aurora.regenstrief.org/~ucum/ucum.html	Optional
53	Duration of pregnancy	The gestational age of the patient at birth	The total number of weeks starting from conception and ending with a birth based on last menstrual period (LMP), not physical examination.	Numerical number- Number of weeks 1, 2 etc.			Optional
54	Number of pregnancies	For female adult patients, the number of pregnancies total, including living children, deceased children, and abortions (spontaneous and therapeutic)	The number of times, including this event, where a female participant conceived and became pregnant regardless of outcome.	Numerical number- Number of weeks 1, 2 etc.			Optional
55	Number of live births	For female adult patients, the number of live births	The number of live births the participant has experienced.	Numerical number- Number of live births 1, 2, etc.			Optional

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56	Number of living children	Number of living children	The number of children currently alive.	Numerical number-1, 2, etc.			Optional
Anthropometric							
57	Current weight	Current weight in grams, kilograms, ounces or pound	The number that describes the vertical force exerted by the mass of an individual as a result of gravity. plus second caDSR item for units: The Unified Code for Units of Measure symbols that represent a determinate amount or quantity used as the standard of measurement for the vertical force exerted by the mass of an individual as a result of gravity.	g kg [lb_av] [oz_av]	The Unified Code for Units of Measure (UCUM)	UCUM: http://aurora.regenstrief.org/~ucum/ucum.html	Optional
58	Current height	Current height of the patient	The number that describes the vertical distance of an individual. plus second caDSR item for units: The Unified Code for Units of Measure symbols that represent a determinate amount or quantity used as the standard of measurement for the vertical size of an individual person.	m cm [ft_us] [in_us]	The Unified Code for Units of Measure (UCUM)	UCUM: http://aurora.regenstrief.org/~ucum/ucum.html	Optional
Patient Reported Outcome							
59	General health	General health measured GLOBAL01: In general, would you say your health is...	A person's stated perception of their general health.	Excellent Very good Good Fair Poor	PROMIS SF v1.0 - Global Health:	https://www.assessmentcenter.net	Optional

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60	Physical functioning	PFA01: Does your health now limit you in doing vigorous activities?	A person's stated perception of their physical functioning.	Functioning Not at all Very little Somewhat Quite a lot Cannot do	PROMIS SF v1.0 10a - Physical	https://www.assessmentcenter.net/.	Optional
61	Pain	How much did pain interfere with your enjoyment of life?	an unpleasant sensory or emotional experience associated with actual or potential tissue damage	Not at all A little bit Somewhat Quite a bit Very much	PROMIS SF v1.0 - Fatigue 6b:	https://www.assessmentcenter.net/.	Optional
62	Fatigue	FATEXP20: How often do you feel tired?	assesses fatigue from mild subjective feelings of tiredness to an overwhelming, debilitating, and sustained sense of exhaustion that is likely to decrease one's ability to carry out daily activities, including the ability to work effectively and to function at one's usual level in family or social roles	Never Rarely Sometimes Often Always	PROMIS SF v1.0 - Fatigue 7a:	https://www.assessmentcenter.net/.	Optional

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63	Depression	EDDEP 29: I feel depressed...	assesses negative mood (e.g., sadness, guilt), negative views of the self (e.g., self-criticism, worthlessness), negative social cognition (e.g., loneliness, interpersonal alienation), and decreased positive affect and engagement (e.g., loss of interest, loss of meaning and purpose).	Never Rarely Sometimes Often Always	PROMIS SF v1.0 - Depression 8b: Never Rarely Sometimes Often Always	https://www.assessmentcenter.net/.	Optional
Medications, Devices, and Health Services							
64	Current medications	A list of all current medications that a patient is taking at the time the registry is updated	Text name of agent or procedure that is not part of the protocol regimen, and are generally used for treatment of preexisting conditions or symptoms, and for adverse events.	Name of medication as prescribed by the doctor	RxNorm	http://www.nlm.nih.gov/research/umls/rxnorm/ http://mor.nlm.nih.gov/download/rxnav/rxnav.jnlp http://www.fda.gov/Food/FoodSafety/Product-SpecificInformation/MedicalFoods/default.htm http://www.fda.gov/Food/DietarySupplements/default.htm	Optional

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65	Dietary supplements and medical foods ³	Dietary supplements and medical foods that a patient is taking at the time the registry is updated	Text name of agent or procedure that is not part of the protocol regimen, and are generally used for treatment of preexisting conditions or symptoms, and for adverse events.	Dietary supplements and medical foods as prescribed by the doctor	Secretary's Advisory Committee on Heritable Disorders in Newborns and Children & Food and Drug Administration (FDA) definition of Medical Foods	http://www.hrsa.gov/heritabledisorderscommittee/correspondence/tableofconditionsandmedicalfoods2.htm & http://www.fda.gov/Food/FoodSafety/Product-SpecificInformation/MedicalFoods/default.htm	Optional
66	Major Surgeries	Has the patient had any major surgeries, defined as those requiring general anesthesia, since his/her's last registry update ?	The indicator of whether or not a patient has undergone an operative procedure on organs, regions, or tissues in the treatment of diseases involving the use of general anesthesia since the patient's last update of his/her registry . Definition of "major surgery": A procedure or activity requiring general anesthesia that produces an effect, or that is intended to alter the course of a disease in a patient or population.	Yes No Unknown	See accompanying document for HL7 table 0163, here augmented by "Unknown"		Optional
67	Hospitalizations	Has the patient ever been admitted to the hospital due to this rare disease or condition?	The yes/no indicator that asks if the patient has been admitted to the hospital and observed over time due to this rare disease or condition.	Yes No Unknown	See accompanying document for HL7 table 0163, here augmented by "Unknown"		Optional
68	Hospitalizations - Quantity	Number of hospitalizations due to this rare disease or condition	The number of times the patient has been admitted to the hospital and observed over time due to this rare disease or condition	Number of hospitalizations (integer)			Optional

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Minimal Common Data Elements (CDEs)**

Element Number	Element Name	Question Text	Element Definition	Permissible Values	Data Source and/or Data Type	Link to Data Source and/or Data Type	Elements selected as "Required" by the steering committee are marked v
69	Assistive devices being used by patient	Specify the type of assistive devices reported by patient or representative	The text that describes the assistive devices used by the patient. Assistive technology device means an item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of participants.	List the name of the item, piece of equipment, or product system	Partial source = Healthcare Common Procedure Coding System (HCPCS). HCPCS Level I = AMA's Common Procedural Terminology (CPT-4)	https://www.cms.gov/HCPCSRReleaseCodeSets/ANHCPCS/list.asp#TopOfPage	Optional
Clinical Research Participation & Biospecimens							
70	Patient participation in ongoing clinical trial	Does the patient currently participate in a clinical trial for his/her rare disease?	The yes/no question that asks whether the patient was enrolled on another study at time of entering data.	Yes No	See accompanying document for HL7 table	HL7 table 0163	v
71	Willingness to be contacted to participate in a future trial	Is the patient willing to be contacted to participate in a future clinical trial for his/her rare disease?	The yes/no indicator that asks whether a patient has consented to contacted about future research.	Yes No	See accompanying document for HL7 table	HL7 table 0163	v

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Element Number	Element Name	Question Text	Element Definition	Permissible Values	Data Source and/or Data Type	Link to Data Source and/or Data Type	Elements selected as "Required" by the steering committee are marked v
72	Willingness to be contacted about donating biospecimen (tissue or body fluid) for research	Is the patient willing to be contacted to donate a tissue specimen, body fluid, or other type of biospecimen for a future research study?	The yes/no indicator of the patient's willingness to consent to donate biospecimen which includes body tissue and fluid.	Yes No	See accompanying document for HL7 table	HL7 table 0163	v
73	Patient previously donated biospecimen (tissue or body fluid) for research	Has the patient previously donated a tissue specimen, body fluid, or other type of biospecimen for research?	Whether the patient donated a sample of tissue or body fluid such as: blood, saliva and urine that was taken for research purposes.	Yes No Unknown	See accompanying document for HL7 table	HL7 table 0163	v
74	Type of biospecimen donated	If a biospecimen has been donated previously, specify whether the biospecimen was tissue or body fluid	Text term to describe the type of biospecimen used for a laboratory test.	Tissue Bodily fluid Both Unknown	HL7 Table 0487	Http://www.hl7.org/	v
75	Location of biospecimen donation	Name of the hospital/clinic where biospecimen was donated	A character string that describes a building or place that provides a particular service or is used for a particular industry.	Text	HL7 TX data type	Http://www.hl7.org/	Optional
Contact & Communication Preferences							
76	Patient preferred Method of communication	Patient preferred method of communication	The terms that describe the means of a process or procedure for the exchange of information between people by speech, signals or writing.	Sign Language Spoken Language Written Language	HL7 ST data type	Http://www.hl7.org/	v

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Element Number	Element Name	Question Text	Element Definition	Permissible Values	Data Source and/or Data Type	Link to Data Source and/or Data Type	Elements selected as "Required" by the steering committee are marked v
77	Patient preferred method of contact ⁴	Patient preferred method of contact	the type of technique related to the more desirable method of contacting a patient.	PH -Telephone FX -Fax MD- Modem CP -Cellular Phone BP- Beeper Internet-Internet Address (email) Mail- Postal mail	HL7 Table 0202 (amended)	Http://www.hl7.org/	v

¹City, town or village name is needed if one would like to develop, a voluntary Global Unique Patient Identifier, with 100% accuracy (GUID):
http://ndar.nih.gov/ndarpublicweb/Documents/NDAR_GUID_MANUAL.pdf

²Age is represented as units of the Uniform Code for Units of Measure (UCUM) e.g. 2 weeks as: 2^wk&&UCUM 6 months as: 6^mo&&UCUM and 34 years as:34^a&&UCUM

³At this time, there is no complete list for medical food and comprehensive list for dietary supplements.

⁴HL7 Table 0202 (Telecommunication Equipment Type) (amended) Value Description: PH -Telephone/FX - Fax/ MD - Modem/ CP - Cellular Phone/ BP - Beeper/ Internet - Internet Address (email)/Mail - Postal Mail